

Presentation for Sydney Nov 2009

My name is Maureen McLeish and I am the mother of three children. One of my children, Lauren has a disability due to a stroke at birth and consequently she has a mild intellectual and physical disability. She is 25 and lives at home in Glen Iris, a Melbourne suburb, with my husband Murdoch and myself. We own a small printing business. I have never worked in the disability field nor have I ever worked for any service provider.

Our story is most inspired by Lauren. Her own ideas around having the same life as her siblings, and her will and determination to be fully included in all things in her community. So for us as parents, the main focus is pretty much the same for all our children. The heading for Lauren's life story would be "For Lauren to get a good life in the community".

Lauren's early years were full of everything disability. This was not our idea. It just happened that way as she was very ill and needed lots of care and so for her to get a good life, we seemed to always be at doctors, any number of therapist's, special play groups and so on and it was difficult to differentiate between meeting her needs for her health and including her in the main stream. We seemed to be heading down a path that labeled Lauren with all things "Special" This was not what she wanted and not what we had envisaged for our little girl.

So when she left school, we were most encouraged by the availability of FFYA funding being available to assist Lauren. This post school options funding was applied for in a bevy of form filling, and if I had known then what I know now, I would have applied for more than I did, as Lauren's needs are not the same now and it is very difficult for a parent to envisage what their disabled child's needs might be in the future. At 18, Lauren's needs were allot different to what they are now at 25, and presumably they will be different again at 45.

So. I went along to a post school Options (sort of) display/exhibition for our region (southern) There I listened and learned and picked up flyers from TAFE's Day Services and Service Providers and set about reading and learning what options would give Lauren the best chance at getting her good life in the community. Everything looked so positive in the information I read. I presumed with the assistance of the FFYA she would be able to achieve this! A little naive, you may think...But "HOPE" goes along with being a parent of a young woman with a disability!

We enrolled Lauren into a TAFE program, It was for the young ones with special needs. Another "special thing." Where she really just continued her education, but it was only for three days and I was thinking the funding would be available for Lauren to use every day, as her disability needs supporting every day. However, the funding went directly from DHS to the TAFE and was "bucketed" and used for everyone, even if the others didn't need as much support as Lauren - and even if Lauren needed supporting outside the TAFE - it still went there.

This was not what I had read in the little flyer that I had picked up at the information day some months earlier. So, while there was allocated funding for Lauren, that said in the brochure it would be “tagged to her” - we and she did not see it, or know how much there was, or what it was buying or if there was any funds available for her to be supported one to one...for instance, to assist her to get a job – Which is what she wanted.. She actually didn't want to be at TAFE, she actually was hoping to get a job but this option needed support.

From then on, I seemed to be on a mission.. Sometimes I felt like it was a WAR more than a mission, and it took allot of bloody mindedness, determination and perseverance to get where we are now.. This should not be everyone's story, and it isn't, because most parents don't know what is available to them and as far as I have learnt, they will never know what is available to them if the keepers of the funds (be that a service provider, TAFE, or DHS) don't tell them! That they have options , The money is there to benefit the person it was applied for and it was allocated to.

So my first phone call was to the TAFE. I wanted to know how much funding they actually needed for the 3 days that Lauren was there. They couldn't tell me. Many calls later I was directed to the DHS Southern and my thoughts were we could split the funding and pay the TAFE for the 3 days and then with the left over we could pay a support worker for assistance to get Lauren a job.

From here I could write a book!

This was like pulling teeth and seemed far too “out there” for the woman in southern DHS to even contemplate helping me.

Around this time I had been to a Michael Kendrick Day at Melba Support Services and met the wonderful Deb Rouget who became my rock and encouragement. With Deb, we had arranged for Melba to hold the funds that DHS would release and after about 6 months of pleading, begging and groveling to DHS, they eventually sent some of the funds to Melba Support Services and I have no idea what happened to the TAFE funding or how much they got as no one could tell me.

So we set off with what was the equivalent of two hours funding. That was all they could give to Lauren for a support worker because the service provider wanted their little slice off Lauren's cake as well. This left a tiny window of two hours funding per week for Lauren.

Things had to change.

At home we had a very unhappy TAFE student who was marking time and watching a hell of a lot of TV during the day. I was trying to get out the door to work, and we needed help!!

So, after 18 months of TAFE, Lauren left. By then we had organized for all the funding to go to the service provider. I was most relieved and very happy, Melba could do any liaising as far as I was concerned. With the entire encouragement still coming from Deb Rouget, we had joined a small family governed group. All the families had their funding at Melba and we had all the say and control over our support workers and we had employed Deb as our coordinator of our small project. This was new and innovative and the start of self directed funding working well.

The project thrived and Melba was extremely supportive of the families and we could receive statements of our funding at any time. These statements took a rocket scientist to read, and were always a few months behind, but we were grateful as we were used to not receiving anything, and in speaking to other parents who didn't have this arrangement, we were definitely the lucky families!

With the individual support package now available to us, Lauren started to get her good life in the community.

We employed support that was paid for with her funding that now went from DHS to Melba who took all the fiscal responsibilities through the 1 x 1 project. They also took a percentage of Lauren's funding to pay for the administration. This seemed fair to us at that time. Good co-ordination got Lauren away from the daily TV watching and into her community where she still is. There is lots more to her life now than an unhappy TAFE experience.

This funding arrangement was working well for us for about 5 years. There was a problem with finding coordinators as after two years of assisting us to get started, Deb went onto other things and we had to find a new coordinator. We actually had 4 coordinators in as many years, and it was apparent we needed to pay them more to make the position attractive. This meant more of our funding going in what I realized was becoming "indirect support" So funds were being extracted from Lauren's support dollars, for coordination, training of support workers, and some hidden extra's. I could see that if I continued, this amount would quickly become \$500 a month and that would be coming out of Lauren's funds.

I had to assess "was this really supporting Lauren and was it worth it?"

1x1 is a family governed group that we started from scratch as a group of friends all working towards the same goals of inclusion. We undertook the responsibility of making sure agreements between services, families, funding etc. were all sound and in doing this we left out one thing. The possibility that this group might not work for everyone forever! People and circumstances change constantly and I started to recognize this was happening to our family.

I was disappointed that I had to leave 1 x 1. I didn't want to let my friend's down but I needed to put Lauren's interests first.

1x1 was something I was very proud of. Our group of 7 families had created something that was THE only and best way for families to get individual support working outside the service system at the time. It wasn't a day service, it was something unique, but it was expensive. It was very expensive. But, until Direct Payments came along, it was the best option..

Running alongside the time we were in the 1 x 1 project with our funds going to Melba was the opportunity for Lauren's funding to come directly to us. The direct payments pilot had started in Southern region of Melbourne and our family was invited to be a part of the pilot.

With the idea of us managing Lauren's funding I couldn't wait to get started! The Individual Support Package would now come to support Lauren completely. It had taken 6 years for us to go from not knowing how much Lauren's funds were, how much was being used - and on what it was being spent, to having all the funds available to us to spend on Lauren to get a good life in the community and no one taking any of the crumbs!

I spoke to Melba about how direct payments could work. I had envisaged this might be an opportunity for Melba to experiment as well. I could be the guinea pig here. Our family was being supported by 1 x 1, and as WE now had the money so how could Melba support us as we went onto direct payments? This was very difficult for the service provider. The way direct payments works is for the service provider to invoice the client after the service has been carried out. Melba insisted I pay the amount of \$350 a month IN ADVANCE so they weren't out of pocket as they had to pay the coordinator and administration costs. If Lauren needed added support we would then be billed for the extra services when they were accrued. My new statement was looking horrific and no one could ever tell me exactly where I was up to. For some reason I owed more and more money as the original \$350 was not enough to cover the coordination fee. This was getting ridiculous and then when the coordinator resigned the new coordination fee was going to be raised to \$500 a month and so we were out of there! Lauren's funds were being pushed to the limit. We had an opportunity to coordinate her life ourselves so we grabbed it. Unfortunately the service provider couldn't, at that time, accommodate what I wanted/needed for Lauren.

1x1 had become too expensive and sadly we resigned.

I have always been confident with my own money and often thought I could do a whole lot better managing Lauren's funds than anyone else, be that the DHS, the TAFE or any service provider..

My husband and I run a small successful printing business, we're not broke. I manage my household budget and have for almost 38 years. Sometimes things are a bit tight, but I usually manage through the tight spots with a bit of financial maneuvering.

Lauren's funds would be child's play!

You do not need to have a small business back ground to do this. You do not need to have knowledge of Excel and print off spreadsheets. In fact you don't even need computer knowledge, but it does assist you if you wish to have all these things. Especially for paying the bills over the computer. This is a time saving if you can do this.

So, for us to get started.

Firstly we had to devise a suitable PLAN that would cover all bases of Lauren's life. It could be flexible and appropriate, and it was planned to relate to her needs, aspirations and of course her funding.

At first it was exciting, as we could purchase supports that were really relevant to Lauren. She has a support worker who assists when needed at her voluntary position, and at her paid position. Also, a fitness trainer, who accompanies her on a walk - and some assistance with hand therapy. She goes to a gym and to hydrotherapy classes and she has podiatry and Myotherapy as needed. She's a member of Kangaroo's football club, weight watchers and we are looking out for some cooking lessons.

There has been some discussion around how much time this takes for us to handle.

Well, I would like to tell you a little around what it actually entails as a recipient of direct funding.

When we first came onto the project Centrelink and the ATO hadn't given full approval to DHS regarding funding influencing Lauren's pension, so it was decided the best course of action was for the account to be put into my husband and my names. Since then Centrelink and ATO have come on board and this is no longer a problem and the funds for support do not affect Lauren's pension or our income. However, we have decided to leave the funding set as it was initially, because we are trying to teach Lauren the difference between her own account and her funding account, and as she has some issues around trying to figure out the money in her purse on any given day, we feel at this stage it is best to keep the control in our hands.

So, how it works for us is.

My husband and I both have a card attached to the account and we pay for any care, services and needs with that card. Lauren can take a card as well to purchase things like a swim or a cooking class. Keeping receipts is essential and she has learnt that responsibility. The rest, I B-Pay. I am often asked if this is time consuming, and I have timed it, and it takes about 20 minutes a month.

I reconcile the accounts while I am paying any other accounts at the computer like I do every month, or when I get an account that needs paying. I then print off a receipt and staple it to the account and put it in a plastic file under the relevant month.. Simple.

There has been no confusion so far and I feel we are managing this system just fine. Initially, I was a bit over the top with my enthusiasm, but I've calmed down. Eventually, our plan is to assist Lauren in recognizing the difference between paying for therapy and buying a DVD, that will come. In fact we are almost there now. As she has learnt so much in her 25 years that we never thought she could learn. So, in the future she can manage her own support funding, as she is learning to manage her life.

I am forever mindful that it is only money, and money alone will not buy Lauren a good life, but it is an excellent tool to assist her in achieving her goals.

I recommend direct payments for anyone who would like to have more say and control over their own life.